

GSNV UPDATE

February 2004

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GSNV NEWS

GSNV Anniversary

Join us to celebrate 5 years of the GSNV on Sunday 1st August! We are planning speakers, awards, entertainment for the kids (and adults!), a fabulous lunch and the opportunity for GSNV members to meet and re-acquaint. This will be a day to reflect on what we have achieved and celebrate where we are now. Put the date in your diaries now! More details will be available in the coming months. Volunteers to help with the organisation would be greatly appreciated, so contact Eilís or Jo in the GSNV office on (03) 8341-6315 or email info@gsnv.org.au if you are interested.

GSNV grants

Brenda Ryan, Information Officer at the Motor Neurone Disease Association recently sent our news of the groups' most recent achievement. The MND Association of Victoria received a \$400 grant from the GSNV for the update of the leaflet on familial MND, called *Guidelines for Predictive Testing*. The project was finished last year and we congratulate Brenda and the MND Association on a job well done! This year's Special Project Grants round opens soon-look out for the forms.



WORK

Auslan at Work

This new service offers to teach Auslan (Australian Sign Language) to business organisations in Victoria whose staff may need to interact with Deaf People, either customers or workmates. A qualified Auslan Teacher will come to your workplace and facilitate a course that meets the needs of your business. For details contact Melanie Wells by fax on (03) 9510 4449 or by email admin@vcod.com.au

PLAY

Companion Card

The Companion Card launched by the Department of Human Services, is up and running! The scheme promotes the right of people with a disability who require a companion, to fair ticketing at Victorian events and venues. Participating organisations will issue the cardholder with a second ticket for their companion at no charge. If you would like to find out more visit www.companioncard.org.au or call 1800 650 611.

Arts Access

Arts Access provides access to arts and cultural activities for people with disabilities. The Arts Access EASE ticket service offers practical information, personal service and affordable ticket prices to ensure more people can attend arts and entertainment events.

- **Individual Membership (\$25 a year)** is available to all people with a disability or chronic illness.
- **Group Membership (\$35 a year)** is available to people living in supported accommodation and community groups (servicing less than 20 people) in the area of disability, disadvantage and health.
- **Organisation Membership (\$55 a year)** is available to organisations working in the area of disability, disadvantage and health.

For more information visit www.artsaccess.com.au Alternatively call 03 9699 8497 (voice) or TTY 03 9699 7636 during EASE office hours Monday to Friday 10am-4pm. Email contact: ease@artsaccess.com.au

SIBLINGS

Your Shout

Is a website created by young people who have a brother or sister with a disability or chronic illness, including bereaved siblings. The site aims to offer adolescent siblings the opportunity to tell their story, and in doing so, find positive connections with peers in similar situations to their own. The site is in the developmental stages so either contact Miranda Smith at mirandas@acd.org.au or phone her on (03)9500 1232 for more information or visit www.yourshout.org.au to have your say.

Siblings Directory Online

The Association for Children with a Disability (ACD) also has an online directory of siblings programs in Victoria which you can search by region for programs in your area. Visit www.acd.org.au or call (03) 9500 1232.

BOOKS AND SITES

Nhip Cau

Nhip Cau is Vietnamese for 'Through the Maze', now available from the Association of Children with a Disability (ACD). To order copies contact the Vietnamese Community Consultant at ACD, Sy Tran on (03) 9500 1240 or email syt@acd.org.au. Did you know you can download 'Through the Maze' from the ACD web site? Other booklets 'Helping You and Your Family', 'Supporting Siblings' and 'National NoticeBoard' are also available on the site as pdf documents. Visit www.acd.org.au or call (03) 9500 1240.

Tony McDonald's Survival Guide

Every child is an individual. To help children reach their maximum potential, parents need love, patience and a sense of humour. Our very own, Tony McDonald has used her experience as a mother, a special needs teacher and an advocate for people with special needs to write this collection of articles that we hope will be useful to other families who travel the same road and experience many of the same challenges. A copy of Tony's book will cost you \$10.00, which includes GST and postage. To order your copy visit www.dsav.asn.au or call (03) 9486 2377 or 1800 654 013.

The Capabilities Dialogues

Is about a diverse group of Australian people with disabilities and their families and friends in the Cooina Family Support Group. This book gives inspiring examples of how people can help each other, not just to cope, but to expand their horizons and have fun. To order a copy of The Capability Dialogues contact Cooina Family Support Group on (02) 6056 4844 or email cooindawodonga@optusnet.com.au

Website

www.disabledparents.net

This site provides information, resources and support to parents with disabilities. Information on the website includes adaptable parenting products, toys, recreation, magazines and periodicals.

UPCOMING EVENTS

Having A Say Conference: 2004'Leading the Way

VALID is funded by the Victorian State Government to provide peak representation of adults with intellectual disability and to operate an advocacy support service for adults with intellectual disability, their families/carers and advocates. 'Having a Say 2004' will run from Wednesday 17th to Friday 19th March, at Kernot Hall (Gippsland TAFE) in Morwell. The program will include: Come & Try Activities, presentations by people with disability, FM Radio and Workshops & Discussion Groups. More information will be available soon, so keep an eye on the conference website www.valid.org.au or contact VALID on 03 9416 4003.

Brochure Workshop

Everything you wanted to know about creating or updating brochures and facts sheets will be revealed in a workshop to be held on Wednesday 24th of March on the 10th floor of RCH. Join MaryAnne Aitken from the Genetics Education Unit to discuss her Top 5 Hot Tips. Look out for your invitation in the mail soon.

Genetics and Population Health Conference

This meeting will be held in Fremantle WA from August 8-10th, with a focus on improved health care delivery in less developed countries and in migrant communities. Thalassaemia will be one of the major disorders discussed because of the scale of its impact on individuals, families and communities and on national and community health resources. If this isn't enough to entice you, our own Eilis Hughes has been asked to present!

Planned topics include:

1. The rationale and requirements of Public Health Genetics programmes
2. Intra-community marriage and inherited disease
3. Diagnosis, treatment and prevention of alpha and beta thalassaemia
4. Disease registries and data linkage
5. The design and implementation of community-based Genetic Counselling and education programmes
6. Community involvement in the prevention of inherited disorders
7. Future strategies for the treatment of common genetic diseases

For more information visit: www.geneticsandpopulationhealth.com

GROUPS' EVENTS

MD Seminar

The Muscular Dystrophy Association is holding its annual seminar of topics ranging from Clinical, Respiratory, Research, Orthopaedics and much more. For more details, contact the Muscular Dystrophy Association on 9320 9555 or by email info@mda.org.au

Australian Leukodystrophy Support Group AGM

Will be held on Monday 23rd February at 8pm on the 10th floor RCH, Flemington Rd, Parkville. Guest Speaker Andrea Murphy from Very Special Kids will talk about the effects on a marriage that having a chronically ill child brings, bereavement issues and sibling support services. For more information call (03) 9548 7070 or email leuko@vicnet.net.au

YOUR SAY

Improving Services

Helen Tossell is the Severe Behaviour Issues Project Worker at The Association for Children with a Disability. She is keen to hear from parents wanting to contribute stories and ideas about how to improve the service system for children with severe behavioural difficulties. Contact Helen at the Association office on 9500 1232 or 1800 654 013(rural callers) or by email helent@acd.org.au

REMINDER

Next Committee Meeting

Monday 16 February at 6pm

Conference Room B

10th Floor RCH, Flemington Rd Parkville

All members and interested parties are very welcome to attend our meetings!

For more information on anything you've read here, please contact Eilís or Jo in the GSNV office on (03) 8341-6315 or email info@gsnv.org.au